国外小儿肠造口术后照护者负担及护理管理现状

The current situation of caregiver burden and nursing management after pediatric colostomy surgery abroad

【摘要】小儿肠造口术是小儿肛肠先天畸形、肠坏死合并休克、腹腔广泛感染等急腹症、以及肛周外伤的常见手术方式。而肠造口患儿因缺乏自我护理能力，术后造口护理等必须高度依赖其照护者，在一定程度上造成了照护者生理、心理负担。目前国内对于小儿肠造口患儿术后照护者负担方面关注较少。该文通过查阅外国文献，阐述了国外照护者负担观点的演变、照护者负担的评估工具、分析照护者对造口护理的了解情况及需求，总结国外医疗机构对其的护理管理措施，并提出展望，期望进一步完善小儿肠造口家庭护理管理工作，以减轻照护者负担。

【关键词】肠造口术；儿童；照护者负担；家庭护理；护理管理

【Abstract】Pediatric colostomy is a common surgical method for acute abdominal diseases such as congenital anorectal malformations, intestinal necrosis combined with shock, widespread abdominal infections, and perianal trauma in children. However, due to the lack of self-care ability, children with intestinal stomas have to rely heavily on their caregivers for postoperative stoma care, which to some extent creates physiological and psychological burdens for caregivers. At present, there is relatively little research in China on the burden of postoperative caregivers for children with intestinal stomas. This article elaborates on the evolution of caregiver burden perspectives abroad, assessment tools for caregiver burden, analysis of caregivers' understanding and needs for stoma care, summarizes nursing management measures for caregivers in foreign medical institutions, and proposes prospects for further improving home care management for pediatric colostomy to reduce caregivers' burden.

【key words】Enterostomy; Child;The burden of caregivers; Family care; Nursing Management

前言

小儿肠造口术是小儿肛肠先天畸形、肠坏死合并休克、腹腔广泛感染等急腹症[1]、以及肛周外伤的常见手术方式[2]。由于肠造口患儿缺乏自我护理能力，出院后的肠造口家庭护理须依赖照护者完成[3]，给照护者带来一定程度的身心负担；但目前国内有关照护者负担的研究较少，缺乏适合我国国情的减轻照护者负担的小儿肠造口术后家庭护理指南和健康教育材料。研究表明，基于多媒体应用等护理管理程序可提高家庭护理效能，同时降低造口术后并发症的发生率、减轻照护者负担[4]。鉴于近几年国外有关照护者负担及护理管理的研究日趋完善，现将其关键信息进行系统分析及综述，以期对我国相关工作的研究和推广提供依据。

1. 国外小儿肠造口照护者负担的影响因素

1.1. 家庭及社会支持

近年来，国外照护者负担逐渐受到重视。一项质性分析中，照护者均表示肠造口的照护在一定程度上造成家庭经济负担及社会关系的困难[5]。大部分父母能够逐步接受小儿肠造口，少数认为无法接受的，主要是由于社会孤立感，包括异味、造口的频繁护理和造口并发症等[6]。在发展中国家，儿童肠造口对家庭稳定性有一定影响，造成部分家庭离异，照护者表示不得不离职来护理小儿肠造口[7]。对于收入不稳定、医疗设施不易得的家庭，赴医疗机构解决小儿肠造口并发症等问题会加重家庭经济负担[8]；大部分信仰穆斯林教的家庭，照护者会将其视为亲密社会关系中的一种惩罚[9]。有研究表明，此类家庭中母亲的创伤后应激障碍综合征的患病率（23%）明显高于父亲（5.3%），因此，有必要在家庭随访中评估父母的心理状态[10]。

1.2. 照护者受教育的程度

索马里的一项调查显示，16 位小儿肠造口照护者的平均年龄为 32.5±4.2 岁。其中 75%（n=12）照护者因接受教育程度较低，而影响照护者对肠造口知识的掌握[9]。照护者主要是对造口用品的了解不足[11]、对造口相关家庭护理操作的准备、

了解、参与等有限[12]。而在小儿肠造口术后护理中，造口术后并发症也是常见且严重的护理问题，如高排量造口、造口狭窄、造口脱垂等，都可能会造成造口患儿营养不良、肠梗阻、造口缺血坏死等症状，从而影响患儿疾病的恢复进程[13-15]。因此，以易理解的形式做好照护者的知识宣教及操作培训很重要。

1.3. 医疗系统因素

土耳其一项面对其 155 名急诊儿科护士的调查究表明，该科最常遗漏的护理实践中包括结肠造口术治疗（37.4%）和出院宣教（24.5%）；由于护理人力资源紧张，结肠造口护理等出院宣教常不被重视，这意味着小儿肠造口照护者由于缺乏相关专业知识，出院后将面临造口护理难题[16]。小儿造口形成后，必须由家中的照护者为孩子提供造口护理，因此，照护者对持续的造口护理知识及技能教育的需求日益凸显[17]。研究表明，照护者越来越关注术后患儿生活质量、性别认同、手术方式的影响；且许多患儿需要持续的多学科护理直至成年[18]。肠造口专科护士紧缺[19]、偏远地区医疗资源难获得[8]等因素，均会在一定程度上加重照护者负担。

2. 国外小儿肠造口照护者负担的评估工具

相关评估量表对于评估小儿肠造口照护者负担以及护理管理效果非常重要；便于监测在不同阶段的照护者负担程度，以及护理干预的适当时机和必要措施。父母压力量表(Distress Termometer for Parents’,DT-P)是经验证较可靠的评估工具，用于评估小儿肠造口父母的负担程度；包括 6 个维度，即：实践、社交、情感、生理、认知和育儿（婴儿或蹒跚学步的孩子）；每个维度的严重程度（0=无痛苦；10=极度痛苦），其中分数≥4 则认为有相关照护者负担[10]。此量表与其他的心理评估量表也有较好的相关性，如：创伤后应激障碍疾病自评量表(Self Rating Scale for Posttraumatic Stress Disorders questionnaire,SRS-PTSD)、焦虑自评量表（self-rating anxiety scale,SAS）、抑郁自评量表（Self-Rating Depression Scale，SPS）[20]。此外，照护者负担量表（Caregiver Burden Scale）、与三维心理痛苦量表(Three-Dimensional Psychological Pain Scale,TDPPS)[21]、生活质量量表（Quality of Life Scale）、社会支持评定量表（Social Support Rating Scale），也对照护者负担的评估有较敏感的反应性[22]。

3. 医疗机构对小儿肠造口照护者负担的护理管理

早在二十世纪八十年代，美国出版的有关造口患儿家庭护理的工具书，为照护者提供相关家庭护理及心理护理经验[23]。美国犹他州一项研究表明，多学科协作等措施可以降低肠造口术后患儿再入院率，对照组出院后 120 天内的再入院率为 63%，而在多学科协作组的患儿为 52%（p=0.04）[24]；而在欧洲一项共识中，也认为多学科协作以及医护人员与照护者之间的沟通交流很重要[25]。对照护者实施线上辅助健康教育，可以有效提高其护理能力，减轻照护者负担，降低患儿术后并发症的发生率[26]。而肠造口护理视频的学习方式可提高照护者护理技能和态度。增强照护者信心[27]。增加照护者的社会支持和减少其对疾病的不确定感在一定程度上会对他们的心理负担有积极影响[28]。所以，对家庭护理的干预及护理管理在一定程度上能减轻照护者负担。

4. 国内展望

4.1. 完善小儿肠造口术后照护者负担的评估工具

目前内外均无评估小儿肠造口术后照护者负担特异性量表，而照护者生理及心理负担已是影响造口家庭护理不可忽视的影响因素[13]。可结合照护者负担的影响因素，如家庭社会支持、受教育程度、生活质量、焦虑评估等维度，并将医疗系统因素纳入其中，制订特异性评估工具，从而在医院-家庭延续护理中的适当时机监测照护者的负担程度，并根据结果提出个性化护理管理措施，提高宣教效果、降低时间及人力成本。

4.2. 完善线上护理管理平台的构建

随着信息的高速发展，线上培训及延续家庭护理正在不断完善。基于在线教育的持续家庭护理模式可以有效提高肠造口患者的家庭护理能力和自我效能，从而促进更好的生活质量和心理状态，有效降低出院后并发症的发生率[29]。所以，照护者可能在患儿出院后需要医务工作者提供持续的线上、视频培训为主的多学科家庭护理及护理管理[30-31]。从而进一步提升其照护能力，在理论知识及操作技能方面减轻照护者负担。

4.3. 提升造口专科护士居家护理胜任能力

张洁等的研究表明，造口专科护士在心理护理、信息管理等方面对于造口患者管

理能力需进一步加强，同时也要完善护理操作的教学培训并提升理论教学水平，以提高造口患者的护理管理质量[32]。目前国内已有研究完成造口护士家庭护理胜任能力评价指标的构建，包括知识和技术、综合能力、个人特质三个一级指标[[33]；可以量化评估造口专科护士的居家护理的综合能力，从而促进其提升居家护理能力，有助于为肠造口患儿提供更专业、全面、及时的线下家庭护理，减轻照护者负担。

5. 小结

肠造口患儿的照护者正在成为一个需要受到重视的特殊的群体。目前部分国外照护者对小儿肠造口基础家庭护理知识了解有限，仍需要了解更多护理知识，如造口用品的了解和合理使用、造口护理操作技巧、造口术后并发症的识别等；且存在不同程度的心理压力。建议国内研究者借鉴国外相关研究经验，借用或开发评估工具，结合我国文化背景，重视照护者心理压力，了解照护者需求，运用合理的培训方式，做好小儿肠造口家庭护理管理工作，以减轻照护者负担。

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